

PEDIATRIC PROVIDER RESEARCH RESULTS

WRITTEN COMMENTS – MAIL SURVEY

Question #1:

Please indicate the category which best describes your professional classification.

Other health care professional responses:

- Program Admin.
- Adoption agency
- Long term social worker
- PT
- Social worker
- PT
- Social Worker
- PT
- Addiction counseling
- DME supplier
- Psychiatrist
- PT
- PT assistant
- RN, MSN – Health Coordinator for Head Start
- Social worker
- Audiologist
- PT
- Social worker
- Social work administration
- Medical social worker
- PT
- County social services clinical supervisor
- Juvenile group home manager and case worker
- CPS social worker
- Social worker – intensive in home therapy
- Treatment foster care
- Social worker
- Foster group home
- Social work
- Social worker
- RN – OB/Nursery coordinator
- Psychologist, clinical
- RN
- Administrator/CEO
- Speech pathology
- QMRP/LSW

- Licensed social worker
- Child advocate
- Social worker
- RN
- Speech therapist
- PD case manager
- Social work
- Physical therapist
- Physical therapy
- Long term care social worker
- Medical social worker
- Medical social worker
- Disabilities advocate
- Family social worker
- PT
- Social work
- Grief counselor
- Physical therapy assistant
- Social worker/hospital
- Physical therapist
- Speech/language pathologist
- LSW
- Long term care social work
- Social work
- LSW
- Foster care supervisor, social worker
- LSW
- LSW
- Family services – child protection
- Social worker
- Social services
- Clinic coordinator
- PT
- Social worker

Question #6:

What, if any, barriers do you see to providing services in your community to children with special health care needs and their families. Additional comments:

- State general fund allocation
- Lack of child psychiatrists
- Transportation
- Lack of parental motivation and assuming responsibility
- Not enough services for children who fall in between “too good for this but not bad enough for that”
- Education of physician
- Distance to services
- We could use more money for respite care services for kids
- Dental services for those on public assistance
- Poor availability of psychiatric services and dental services
- Availability of treating professionals (psychiatrists, psychologists, etc.)
- Transportation
- Travel
- Lack of adequate community based specialty beds at intensive care level
- Specific child psychiatrists
- Transportation – financial help so parents can take time off work to go to appts.
- Specific offender groups (sexual)
- Transportation
- Not enough providers
- Don’t know what a normal, healthy home is anymore. Transportation. Family unit education. Not taking responsibility. Addiction. Enablers, lazy, no morals. Disorganized, chaotic lives.
- Transportation to appointments is problematic. No centralized school clearing house for services
- Limited social workers/services
- Residential placement in the community for children with severe profound needs.
- Limited number of providers
- Lack of rec/leisure. Child care after age 12 and sometimes even younger
- Distance needed to travel for services
- Many children who need services do not qualify. MA doesn’t cover certain services
- Accessible housing for young adults
- Transportation/scheduling and work conflicts with providers
- Lack of service providers
- Transportation
- Lack of adequate funding streams, regulations that develop/sustain services
- Home care nursing when medically needed at home (shortage of nurses and staffing problems)
- Transportation

- Having to drive long distances
- Due to travel for services, the need or help with costs and childcare
- Specialists not available
- Waiting periods to see professionals. Lack of funds and resources
- Funding
- Lack of transportation
- Appropriate and early referrals, lack of parental knowledge and information to follow up, untreated mental health needs of parents
- Transportation to services
- Limited physicians specializing in mental health
- Costs not covered by MA/Insurance
- Cost of services- The clients I serve can not afford services or even Medicaid co-pays
- Rural access
- In-school services very limited
- Lack of brain injury programs for children – for example: long term care facility other than a nursing home
- Diagnosis specific eligibility
- Lack of local resources, although slowly improving
- Families living in very rural areas
- Rural, poverty, lack of transportation
- Number of physicians, lack of behavioral services, lack of family support services, not enough foster care availability, funding cuts or caps, little skills training in Fargo area
- Not enough facilities
- Costs for available services
- Daycare
- Local services are not available as needed
- Barrier between private sector and school district
- Lack of resources for timely accessibility, including screening. Fragmented resources. Payment often an issue.
- Transportation for consultation
- Lack of parental cooperation
- Transportation
- Not enough providers
- Limited local resources
- Transportation
- Limited services available
- Access to services – transportation
- Insurance – both MA and private. Parents are trying to do the best they can for their child and the insurance and its rules deplete them financially, emotionally and tolerance.
- No third party payment.
- Transportation

- Limited services/resources. Transportation/distance becomes an issue.
- Distance to providers
- Insurance company limitations on services necessary/appropriate.
- South valley special ed refuses to consider physical needs/physical therapy. Also restrictions from insurance providers.
- Respite care is available but is often times difficult to find caregivers that are specially trained or willing to get training
- Travel/transportation to get to providers since very few in the community. Lack of services in rural areas.
- Poor insurance coverage for mental health services
- Funding for after school services, daycare for special needs in summer, after school, before school and also for kids with mental health needs

Question #7:

What, if any, barriers do you see in the delivery system relative to providing quality health care to children with special health care needs and their families?

- Other barriers
 - Competition between agencies to minimize financial exposure in service poor/working poor
 - Lack of transportation/childcare
 - Distance/lack of transportation
 - Lack of psychiatric hospital for day treatment
 - No local services to meet needs
 - Unmotivated parents or parents too busy trying to put bread on the table to apply for services.
 - Lack of specialists.
 - Not enough providers, waiting lists
 - Need to get physicians one day to rural sites, need rural grants
 - More psychiatrists specializing in adolescent mental health
 - Budget
 - Limited resources/specialists
 - Inadequate funding at all levels
 - Responsible adults – lacking. Addictions. Parent in jail.
 - Distance
 - Limited providers
 - Parents/providers get a run-around when calling human service centers
 - Waiting list
 - Lack of interagency team meetings
 - Funding
 - Funding lack for adequate service providers
 - So many agencies involved – time to keep everyone informed
 - Inadequate financial resources
 - Jurisdictional, regional
 - Travel for services – an outpatient treatment is not cost effective for family because of travel expenses
 - Lack of trained mental health providers who specialize in children
 - Insurance
 - Daycare and education
 - No local services outside of school available
 - Time restriction. Too often direct time is the focus. Case management time is not considered important.

- Lack of culturally-relevant services
 - Mentoring and translation service availability
 - As relates to Native Americans
 - Native American programming
 - Interpreters, CEV's on cultural issues
 - New American immigrants
 - Lack of cultural competency
 - High refugee population
 - Native American culture not respected
 - Prejudice and lack of awareness regarding native issues is still prominent
 - There are limited interpreter services in state. Also, Native American families don't always ask questions and then people just let that go rather than giving information
 - Native American culture
 - Cultural miscommunications and conflicting values
 - No Native specialists, none in tribal/IHS at Ft. Berthold
 - Language barriers, Native American
 - Not specific to native American population
 - Lots of Native Americans through systems that are unfamiliar with culture, cultural differences. Lots of different populations in Fargo – Moorhead area.
 - Providers do not appear to be sensitive to cultural needs/behaviors of families
 - Low population – don't deal with it on regular basis. Language barriers – foreign language – need interpreters. Some sense of community stereotyping.
 - Lack of relevant knowledge by leaders/legislators, etc.
 - Native American
 - Translators can be difficult to access
 - Education for providers
 - At times, especially for non-Indian minorities
 - Lack of awareness and education for health care providers on how other cultures view illness, death, grief and loss
 - A lot of my patients don't speak English
- Lack of coordinated funding system
 - It is a nightmare for parents to get funding

Question #8:

What, if any, services are lacking in your community and should be made available in order to provide comprehensive care for children with special health care needs and their families?

- Early intervention services
 - For kids over 3 who don't qualify for SN preschool
- Mental Health services
 - Need increased number of MH professionals trained to treat children and their families – care needs to be at least adequate
 - Psychiatrists/psychologist
 - Behavior intervention
 - Therapy/family therapy/psychiatric/volunteer drivers/anger groups/sexual abuse groups
 - Access to affordable psychiatric and psychological services
 - Mostly regular resources
 - Pediatric psychiatrist, sexual offender specialist, more group work (anger management, social skills, drug and alcohol)
 - Children's therapy
 - Need to focus more on family
 - Early intervention as lifelong challenges
 - Appropriate counseling for children and parents
 - Very limited access
 - The wait time for appointments/referrals is long!
 - Child/adolescent care (specialists hard to access)
 - Therapists
 - Too long of wait to see
 - Child psychiatry
 - Not enough physicians/appointments out 3-4 months at a time
 - Our small town doesn't have capability for variety of services. I am not aware of what's available. Limited HIS services/lack of psychiatrists, psychologists, funding primarily adults only
 - Psychiatric and therapy for kids
 - Child psychiatry
 - Counseling- have to travel at least 30 miles or more
 - Child psychology
 - In-home parent training
 - Very minimal resources and too specific criteria for youth with SED. Long wait to get services at times – has improved over past 10 years
 - From counseling to psychiatry
 - Overload causes delays
 - Groups, therapy
 - Sexual abuse-individual/group
 - More child psychologists
 - Additional providers

- For those with no insurance
- Diagnosis/treatment lacking
- Adequate psychiatric/psychological assessment beds, TRC licensed through corrections adequate sexual responsibility program relapse/support services in communities
- Long waiting period to be seen by a provider who specializes in pediatric issues
- In-home services
- More specialists
- Family therapy, individual therapy
- Waiting list for even intake is 6-8 weeks long
- Long-term psychiatric care group care, RCCF, RTC for younger children
- Funding is decreasing, resulting in cutbacks.
- Medication gets expensive even if a person has insurance and a supposedly adequate salary
- Schools should make more info available to children on death, dying, grief and loss from experts in these fields
- Psychiatric – behavioral based
- Diagnostic Services
 - Lack of integrated assessment of cases by multiple disciplines
 - Overload causes delays
 - Most specialties
 - Screening processes
 - More autism specialists
 - Not enough child psychiatrists
 - Dental
 - Most sent out
 - Psychiatric services
 - Not always available
 - Across the board, esp. neurology
 - Better physician contact
 - Employability tests
 - Staff availability and time
 - Placement options
 - Testing
 - More expertise – seizure disorder genetics
 - Screening services for MH issues that can be accessed timely
 - Psychiatry and pediatric neurology

- Specialty Pediatric Care
 - Psychiatrist
 - Pediatrician
 - Pediatric orthopedic physicians
 - Ortho, GI
 - Orthopedic issues
 - Closest facility 90 miles away
 - Nursing care
 - Neurologist
 - Ped. Neurologist, ped. Orthopedic surgeon
 - Evaluations
 - Neurology and ortho
 - Pediatric cardiology and pediatric urology
 - Emotional and behavioral and dental
 - None locally – need to go to Bismarck
 - Pediatric neuromuscular support with neurologist
 - Limited pediatric specialists: ped. Neurologists, ped. Orthopedics
 - Lack pediatric care much less specialty pediatric
 - Psychiatric care prior to foster care placement and during
 - Sound, experienced providers
 - Endocrinology, pay care
 - Only one pediatrician in town
 - Endocrinology
 - Additional early Headstart openings, additional specialized caregivers

- Support and discussion group
 - For spina bifida

- Community Education
 - Parenting instructional courses
 - Need more money to get message out
 - Parenting
 - Let community know of services available
 - Juvenile court, doctors, mental health providers
 - Lack of knowledge regarding how to work with mental health challenges
 - What youth need
 - Where services are located. What kind of services are available.
 - More reminders to parents about things to watch for that may be delays.
 - On topics that are relevant to special needs.
 - Awareness of services available to families
 - Across the board, never see or hear of any

- Other Services
 - More group home settings for kids who are between things
 - Dental for those on public assistance
 - Behavior training that can be implemented by parents for the benefit of the child
 - Services to children with TBI/organic brain impairment
 - Transportation to services in larger communities like Williston, Minot, Bismarck and Fargo
 - Special needs daycares
 - Young adult transitional living
 - Dentists. Education in schools. Poor diets by choice – live on junk food by choice – pop in schools. Society's problem – TV teaching poor morals, movies not family oriented, advertising glamorize alcohol, prescriptions and nudity.
 - Services are available, but at very low levels. Transportation is a big issue.
 - Child care and rec/leisure – very big problem as child grows older
 - Transportation, funding
 - Day programs/care for when children are out of school – shortage of sites that will take special needs children/adolescents
 - Fitness classes or 1 on 1 fitness at fitness centers such as the YMCA for children with special needs who no longer need or qualify for therapy services or as an additional service. This is a definite area of need in Bismarck.
 - Facility to provide care to brain injured children (long term with therapy services)
 - Insurance coverage/public assistance programs to make specialists affordable for all
 - More VR workers
 - Assessment center in each region to determine appropriateness of placement for foster care for children with more needs
 - Day care for working parents
 - Prime time daycare for summer and school age
 - There is a shortage of qualified professionals – only two major resources: school and HIS
 - Residential placements that have openings for severe behavior disordered children
 - Funding, increase in services
 - Coordination of services and resources
 - Funding is seriously lacking

Question #9:

What role(s) do you believe the North Dakota Department of Human Services, Children's Special Health Services Unit, should fulfill in serving the needs of children with chronic health conditions and their families?

- Should provide leadership in developing, implementing and managing a long-term plan – 10-20 years for improvement in services to children and their families
- Provision of medical coverage to assist with cost associated with the condition
- Partnership/wrap around program
- Funding additional staff
- Establish special needs daycares
- Prevention. Need programs before child bearing years so can take better care of children and be responsible, otherwise don't have kids!
- Too much abuse of system
- Funding/various programs
- Used to do better job of promoting the whole family's involvement but that requires money, time and staff.
- Provide training for mental health professionals on assessment and treatment of children
- Lack of cooperation with D.D. in grants for children who are not qualified for medical assist. Parents are just over the guidelines.
- To challenge the restrictions of categorial services
- Education
- Advocating human service centers to provide outreach services

Question #10:

If you could make only one change relative to improving care in your community for children with special health needs and their families, what would it be?

- More money available for respite care to provide support services to all families that are requesting respite.
- Need in-home/respite services. Anything that gives the family added support and a break from the situation.
- A pot of money to pay for travel to counseling/medical appointments.
- Less emphasis on private third party payers, however this would require a significant increase in reimbursement from the Medicaid program
- The ability to share information across professionals from different clinics/sites. Also provide parenting classes for those parents who need it.
- More affordable and accessible without long waits to get a child to see a psychologist or psychiatrist
- Making those services more accessible and affordable to those who need them.
- I would have a parent/child advocate go with to the first several appointments to assist the parents in understanding what is going to need to be done and that the advocate will be with them until everything is in order and how the parent can tend to the problem without being overwhelmed.
- People to go into the home to help with care on a long term bases, parenting classes, respite care and specialized day care for older children who can't be left alone.
- Less hassle for children to receive long term care. Insurance companies see therapy services on medical model which requires monthly preauthorization.
- More regular therapies.
- To have one application process for all agencies and to keep caregivers informed of process. Also educate professionals on process.
- Increase funding in all areas.
- Provide home based care and pay for it.
- Multidisciplinary, coordinated care. Family physician/pediatrician, speech, OT, PT, mental health, case management, family therapy.
- Expand knowledge base for professionals in community about the resources that are available for faster referrals.
- Someone who can be available to parents as needed to help them navigate the whole system – medical, financial and on going. Much of what happens is out of the experience, training and time a DD case manager has available to provide.
- More adequate services to children with neuropsychological problems – diagnosis, case management, funding for treatment, rehabilitation.
- I would like to see more focus on early intervention/prevention in the area of mental health. It seems that our current programs are designed to respond after a problem is identified, rather than moving rapidly into high risk families.
- More awareness among parents of signs of delays and acceptance that if delays are noted, therapy is necessary.
- Improved mental health services.

- Funding opportunities – existing local staff in all areas are getting stretched to the limit.
- Just make a simpler system of getting these services rather than every agency having their own set of rules/paperwork/procedures.
- Having a behavioral child psychologist and psychiatrist employed in Williston.
- Easier access to diagnostic services and also more intense/faster diagnosing. Some families struggle for months trying to access an appropriate diagnosis.
- Long term support for parents who are DD
- I would increase funding so more services are available to more families.
- Better accessibility for families needing the services.
- Acting all professionals on the same page.
- More awareness of programs to families that may need the service and promotion of programs to the public – educate
- Have a respite or family support program for families.
- Building awareness. More physicians.
- One barrier I often see is families who need respite hours or support but are unable to get support due to income and not being eligible for MA which restricts services .
- Improve health care for natives on the reservation.
- Educating rural communities as to the importance in finding individuals locally to assist families in their area so that children can remain in their homes, communities and schools. Educating families to advocate for themselves to get the services they need at home, school, etc.
- To have comprehensive services closer not only for children
- Sponsorship of multi-disciplinary clinics
- We have a mental health psychiatrist who comes to our school .some of our children do not qualify for medical assistance. (HIS) will not acknowledge outside prescriptions for these children.
- Funding for support groups
- It's hard for parents to get off work and drag siblings along for appointment one hour drive away. Have child psychiatrists available in town 1-2 times per month.
- Additional group homes. Emergency holding facility (short term holding while awaiting placement)
- Increase funding
- Have more money for DD services. More educational programs. Parents are unaware of what is available to them.
- Coordinated efforts/services
- Alternative funding sufficient to provide level of care needed for the child
- My specialty is mental health and I can only repeat my appeal for training because treatment by competent providers is so critical when working with children, especially very young children
- Easier access to information on where and how to get necessary services.
- Case management follow up; advocate services
- Find dollars to pay for the services provided to children's special needs
- Better access to funds

- More specialists. Dental care is one issue (big time)
- Respite care programs
- More public awareness of programs, support groups, resources, etc.
- I really think multi-disciplinary clinics are a need in this state. Awareness is also a major issue.
- Work with/collaborate with agencies regarding special needs of children and teens when a loved one is ill, dying or has died
- North Dakota is a rural state and families have access to services around the state, but due to limited funding and the distance to get to services and finding services right within your area is limited in the more rural parts of the state.
- Prioritize the populations to be served and the levels of care and then match the priorities to the resources available.
- Increase awareness of available funding for adaptive devices/equipment
- Increased number of physicians, therapists, dentists, psychiatrists that specialize in dealing with children and adolescents and take MA.
- Add child psychiatry
- More group homes for mentally handicapped
- More availability of mental health professionals specializing in adolescents (psychologists/psychiatrists) to low income families. Also, focusing more on inclusion of all family members in treatment when their child is in counseling for behavioral issues (ex: how to parent an ODD/ADHD child)
- Referring them to sources where they would be taken care of adequately
- Speakers to provide information about teenage parenting, services available in the community and how to get youth involved in the community.
- Make health insurance available and affordable to families of children with special health care needs
- Provide support and education to parents
- More services or options for families to go to in times of need, right now there is a need for more child psychiatrists in the Fargo-Moorhead area and also in the outreach areas.
- Some of our physicians are starting to refer to the infant development program. It would be great if we saw more referrals from that area
- Cut throw the red tape, make accessing help more pleasant – paperwork is overwhelming and intimidating (as is the dark lobby and glass cage at Minot Human Service office)
- Help for the family with transporting
- Increased psychiatric and therapy services
- Developing additional supports and assistance for families with emotionally disturbed and behaviorally challenging children. Respite and in home supports are not adequately meeting the needs of these parents.
- Education of services available is so important. Also, income at times limits what is available (especially an average income). Sometimes it eliminates a service because of eligibility guidelines. Shouldn't all children be allowed to participate regardless of family resources?
- Help children/families alleviate poverty

- Preventative services
- Better funding (public and private) to all levels
- Comprehensive diagnostic clinics
- Combination of service availability and education
- Seamless case management that is intensive and can go for several years if need be with overlap into other systems the family/child move within – such as with school
- Better assessments and more placement options for this population
- For youth with serious emotional disorders and their families, I would like to see readily available and accessible respite care, mentors and natural supports in the community
- More coordination between existing clinics/facilities
- Addition of staff
- Community education to build awareness and linking the families and patients to services
- It would be nice to see respite care hours increased for families who need more hours. 13 hours is not always sufficient for families
- Access locally to psychiatric or developmental evaluation in a timely fashion
- Transportation
- Services would be more family friendly. Families would have a bigger voice in developing the plan of care.
- More resources
- Better funding in health care. Free or income based services have too long wait to get in.
- Availability of special needs daycare sites with trained staff
- Improve funding for equipment, supplies, caregivers for children and families
- Drug/alcohol free programs/parties. Wholesome activities for children/families. Back to “family units” – picnics, etc.
- More respite care service available to the families. More public awareness about services available to the families.
- Local pediatrician contact via satellite clinics
- Create a centralized office with information on all services (at the school too)
- Having specialists more available in the area (Williston)
- Since many families are living in rural areas accessibility to major health care facilities is difficult (travel, lodging and childcare costs); funding to assist them is needed.
- Transportation!
- Providing ongoing support for families (i.e. respite, financial, emotional)
- Increased case management such that services more centralized/coordinated with providers more in contact with each other – families get more consistent information/treatment and don’t need to search out assistance/care needed.
- Secure adequate funding to offer some of the above services.
- Additional providers for less wait time to see provider
- Rec/Leisure activities for older children especially during the summer
- Help with transportation costs

- I would make it easier for parents to navigate the system. These are parents with enormous stress – they don't have the time or energy to figure out how to get funding – nor do I!
- Accessible housing for families
- Financial resources for parents
- I think there are some wonderful services in our community. The biggest problem is knowing all of them as a professional.
- Follow up and supportive services
- Funding to upgrade technological needs for programs serving children with special health care needs.
- Support groups for families
- Having the appropriate specialists locally so that families wouldn't have to travel long distances for care, surgery, etc. and there would be better communication between the physicians and those that actually know and treat the child.
- Early intervention allowing for multi/interdisciplinary services vs. transdisciplinary or encouraging families to access the missing services and better communication between EI and medical therapy services.
- Provide financial assistance and case manage children with special health care
- More mentoring
- More awareness of the services that are available out there – specialized possibly
- Leadership collaboration and education to increase advocacy at the legislative and state dept. level, adequate development/coordination of volunteer, charitable, other community projects – services, understanding of services, needs and reduce adversarial relationships (at service level?)
- More respite care for families
- Less hassle in insurance companies – esp. BCBS
- More in-home services, so services are more accessible
- Respite services readily available to parents/caregivers, especially to allow them opportunity to attend education opportunities
- We have absolutely no service for children who are DD w/mental health issues. We need more parenting programs for DD parents to deal with their children.
- Respite for special needs children and siblings. Help with costs to seek available services when not in area.
- To have a physician practicing in this area (Sentinel Butte)
- Have the funds available to provide the services we know we need
- Building awareness and linking families to available services
- More facilities; group homes for 15-25 year olds that are not severe. North Dakota offers only 6 beds for the entire state! Openings are rare. We have to look out of state – away from family!
- Multidisciplinary clinics staffed with specialists
- One-stop shopping
- Affordable transportation
- Adequate respite care and support services
- More funding for psychiatrists
- Increasing awareness of programs

- Improve health care – a better variety of physicians to choose from
- Facilitate ease of communication (family, provider, and payor)
- County involvement for follow-up services when 960's are filed
- Better collaboration of services for clients/families with diagnosed mental illnesses and easier access to services
- Additional services for psychiatric hospitalizations and residential treatment centers for grade school aged children. Some children are moved multiple times because foster homes cannot provide care for the multiple psychiatric issues children have the multiple psychiatric issues children have in foster care.
- Larger group providing wrap around services for wider ranges of special needs, including physical.
- Exercise programs, sports, etc. that don't cost an arm and a leg and are for learning instead of competition.
- Making it affordable for families to utilize these services
- Provide support and educational training to family caregivers who provide the primary care
- Develop a system of supervision whereby masters level mental health professionals can provide services to children and youth – if they are appropriately supervised by a licensed psychologist – and that medical assistance allow payment for those services.
- The greatest barrier is the time it takes to talk to all the payers. Coordinating communication would be a great help.
- Bring more services to Park River
- Decrease/eliminate violence and explicit sexual matters from easily accessible media, ie. TV, video games, computers, internet
- Increase rural awareness and programs/money available to these communities
- Somehow, to let families be aware of this program. Majority of them are not aware of this program until someone mentions it to them.
- Difficult questions for me as I don't work with children very often. The patients I see who are under 18 are usually involved in some type of accident. It is a challenge to find appropriate facilities/care for those teenagers who have sustained a brain injury. A lot of these patients end up going to Minneapolis for further care and brain injury programs. It would be nice if Fargo could have such a facility that would specialize in long term care for teenagers and young adults.
- That individuals know about the services
- The cost of service being decreased so it would be affordable to our low-income clientele
- More flexibility in accepting children based more on need than just diagnosis for either children's special health services and or DD case management
- Additional respite care funding
- More availability of all levels of care for children and their families, up and including necessary out of home care.
- Increase awareness of services/availability
- Better case management

- Working in a residential treatment center, the biggest challenge is after care planning. We have children that need homes to go to, but there's a lack of funding and availability. Foster care/PATH homes are crucial for some children's care, however they're utilized greatly in this community. It would be ideal for facilities/agencies to partner to assist with after care. Without homes available or other facilities, the courts, counties, DHS are left to make decisions of placement which can mean further placement in a state facility or out of state...meaning more money spent for longer term higher structured care that may not be necessary. Managed care also makes planning difficult at times a year of placement is not always enough. This is of course dependent on each case. We have seen some that did not continue in care based on the "1 year: and have seen them to go back into facilities, out of state, in state, higher structure – which can cost the state more money in the long run.
- Have more multi-specialty clinics in Grand Forks so patients don't have to travel
- Better insurance coverage so children with special needs can take full advantage of the variety of services available out there.
- Daycare opportunities for kids with special needs in their own home
- Consider out reach clinics in Grafton area.
- Preventative programming. Respite care services.
- To have a multi-disciplinary clinic available on ongoing bases, but to also include ones for children and families to receive basic assessment and hooking up for services in the community. Right now wait time to get info evaluations is long (several weeks to months) which is also reflective of a service availability in the community.
- Accessibility – ease to get them in to see specialists
- Therapist be given "okay" for case management time. Many of these children and families require time outside the therapy hour.
- Educate schools, families and individuals on mental health issues and services
- Area schools, drugstores, clinics, hospitals receiving pamphlets about CSHS
- Setting up satellite clinics so less travel is required for families.
- Case management.
- More awareness and understanding of complex behavioral and emotional problems
- Expanded health care coverage for families
- Communication between case management and other agencies involved in care.
- Making sure both families and providers are aware of available services.
- More in-home assistance.
- Building awareness of available services.
- Education and available access to services.
- Increase funding for services with case management
- More child specific providers (mental health) especially more services for childhood sex offenders.
- Having a pediatric specialist.
- Community awareness
- Public information and education

- More respite care services
- Streamlined easy to access services – especially specialist in MD field and mental health field.
- More availability of pediatric specialists within ND, less travel for parents to MN for specialty care.
- Availability of services – less wait
- Continue to inform case managers about resources and programs available. Continue to inform families of available services – especially those underserved or under/non-insured families
- Increase awareness of how to access PT services then they have concerns
- Require schools to adequately consider physical needs of students. Require insurance to adequately cover pediatric therapy.
- Provide more pediatric physician specialists, especially pediatric orthopedist
- Provide coverage for health care/testing/services that insurances refuse to or poorly cover
- Services/specialists should be closer
- Psychiatric hospital for emergencies that would also provide day treatment such as schooling and group work with children who are not stable enough to attend public school. I believe the ND state hospital could fulfill this need.
- Make it a priority to inform families with special needs children of what services are available including respite care.
- Continuity of support across service settings for people in crisis. Need more transition support to and from hospitals and/or specialized residential services.
- Be able to make one phone call to get child enrolled in special health needs assistance. Also, more multidisciplinary appointments.
- Educate the public and professionals about needs of these families how to access services and what service are available.
- Revitalize children care coordinating bodies and allow them to be run by non-public entities
- Increases grant money for services. More respite services for families. Better health insurance coverage. Affordable health insurance.

Question #11:

Do you have any additional recommendations relative to improving services in your community for children with special health care needs and their families?

- As a community, region and state, we need to increase and unify leadership and decrease as much as possible the politics of the delivery system. There are too many systems, political and resource distractions that significantly decrease the level of service we can provide. In the DHS system there is tremendous waste in the documentation requirements, both in the electronic and written formats. As with population and level of care, documentation needs prioritization to significantly decrease the time required to bill and describe what has been provided. This will result in an increase in time to serve clients and their families.
- Have money designated for school nurses.
- Encouraging more cultural sensitivity and training for staff working with minorities such as immigrants and Native Americans, as well as recognizing the barriers these populations face.
- Sexual abuse group for children
- More awareness of CSHS needed.
- SEHSC needs to do a much better job of meeting chemical dependency needs for adolescents – they only offer individual therapy – all research supports a group therapy structure.
- Improved awareness of available services/programs in the community and the state
- 1. Physician knowledge of MC ped therapies 2. Provide pamphlets at easily accessible places i.e. malls, movie theater, doctors offices, etc. 3. Increase parent awareness/knowledge to ask/inquire regarding specific fine motor and speech services appropriate for child's age.
- Transportation to services in Grand Forks can be hard at times
- Coordination of services by involved agencies.
- Case management with sufficient diligence and authority to follow through and see that companies and agencies are covering needs of students/policy holders.
- Adequate payment for services.
- Parents do not have an understanding of CSHS and if they would qualify for services and what services are available. Physicians do not assist parents in making application for CSHS.
- Transportation/distance is a real issue. Dental access is spotty at times.
- Services need to be timely and accessible. Families rarely know that a situation is brewing and can wait six weeks for assistance. The situation is generally a crisis and it is nearly impossible to access services for weeks if not longer.

- Your statement that completing the survey will require approximately three minutes of your time may be true, but to take a serious look at the issues involved and to review the multitude of barriers/gaps takes a significant time investment. Additionally, there have been multiple surveys, town meetings, needs assessments done in the past six years (mostly mental health and substance abuse) that have identified the same needs/gaps and have offered similar recommendations. For public sector services, the main barrier continues to be the allocation of state resources, general fund and the state match for federal programs. In my opinion, there are multiple solutions, however each requires making tough but well informed decisions and strong consistent leadership.
- Flexible funding to help with transportation costs and other costs that Medicaid will not pick up. Additional funding for things that insurance will not provide for.
- More and better foster care
- I have a younger brother who is mentally challenged but because he is not bad enough he doesn't qualify for things yet he is not good enough for other things. We need a better system equipped to handle these kids. His age will be 18 but his mind is anywhere from an 8-10 year old. Thank you.
- Funding. Insurance authorization for pediatric home health services.
- Family approach in case management to be handled by special unit within the state level that have specialized training and direct link to medical care – multidisciplinary approach that wraps around the families' needs
- Directory of all pediatric therapy providers in North Dakota or a district number to call to get a referral (name of provider in certain area)
- Not to take over the parent's role – do more educating and teaching to them on how to handle their unique child. Dependence on the system is somewhat of a concern. I work with behavioral problem in children. Parents consistently tell me they are receiving no education in ways to parent their children when they have an ODD, ADHD diagnosis such as behavior mod plans or parenting techniques.
- Increase recreational sports for children with disabilities on an organized bases.
- Overall, I think CSHS does a super job with funding that's available. There is overlap with other programs and this might be a helpful way to rework involvement. The grants are key to keeping clients and professionals connected.
- Payments for health care for families who are just below the guidelines.
- I work a small community clinic in New Town and there is also a HIS clinic. We do run the WIC program for native children but I do not see a large number of children who need special services. I would find data on the number of children and what their needs are of great value. Demographic, epidemiology information on children of special needs in my area.
- Utilizing some type of multidisciplinary paperwork packet so families aren't constantly filling out similar paperwork for agencies who are likely working together.
- Need for more activities/adapted recreational programs for special needs.
- We do OK in Williston but in some of our more rural areas finding respite care providers is tough. It would be nice to have additional funding for respite care as we do have some money but our budgets have been cut

- Increase services for diagnosis and evaluation and follow-up care due to lengthy waiting periods. Many times, it takes months to see a treating professional. Unfortunately, many children ultimately end up needing a higher level of care.
- Respite care is so important – caregivers that are required to be on 24-7 need time to rejuvenate their own spirits. Also income is often lost as children are taken to appointments or if there is a crisis. Would a grant help in this area?
- Partnership between tribal/state government to address special needs of children. Children's needs on reservations are multiplied due to poverty and access issues
- Services should be provided to the individuals who need them rather than who can pay
- Expand funding possibilities for those non-covered medical and other expenses
- Increased funding
- Support and discussion groups
- Often resources are lacking to assist local people from accessing specialty services in Fargo – the usual poverty, single and or unsupported families
- More mid-range (1-6 months) residential care sites for children 13 and younger
- I'm not sure why I was chosen for this survey. I am out of the loop. (social worker)
- There are lots of wonderful services! There is lack of morals – responsible adults not doing their job – they let someone else raise their kids and etc. Human life is not as valued. Bad attitudes. People don't enjoy what they have! Always want more – ads, put you down if you don't have everything. Lots of children suffer because of drugs, alcohol during pregnancy and lack of adequate, loving care as babies and toddlers. Services then help, but are too late sometimes for a healthy, normal child/adult.
- Why can't the elder bus system also be used for disabled kids?
- More in-home support options
- The electronic communications reg. by HIPAA has resulted in many of my colleagues refusing Medicaid/Medicare cases. I work for the state and as such am relatively unaffected.
- Stop assessing normal kids through right tracks program! This should be done at well-baby physician visits! It is a nice idea, but when kids are going without services because of lack of funding we should not be duplicating developmental screenings for normal children. The "hit" rate on this (finding disabled children who have not already been identified by a physician) has to be exceedingly low. Maybe only screen at-risk babies?
- Providers need flexible schedules so that families can be seen other than 8-5 p.m. Medical/dental health care should be available to all children. Funding needs to be expanded.
- Need more dollars for all areas. Severe gap for children age 10-21 regarding speech and rehab services. Also respite and day services for working parents.

- Educate physicians and OB/GYN about the developmental problems “high-risk babies” may endure the rest of their life. Prevention is #1. We want to be proactive vs. reactive in our care. Early intervention is critical in the development of high-risk newborns. Academics start before the birth of a child, not when a child enters school. Prenatal care for “mothers to be” to prevent developmental problems.
- Grants for braces for those families that don’t qualify for CSHS
- Frequently, children no longer require the services or even if they do (insurance is frequently denying the need); but these children don’t have fitness classes/centers that are available to them or who will modify their classes so they can participate. Where do these children go to maintain or increase their fitness?
- Have one entry point to refer parents/families too. Also, be more out in the community.
- Many parents have problems finding day care providers for when they return to work. Also difficult to find adequate day care providers for older children who are developmentally delayed.
- Family support group. Respite care
- We need to quit saying to legislators that we don’t have any unmet needs – so we can have more money budgeted to make services available to all children and families with needs
- We need to find ways to get parents/families of emotionally ill/troubled kids involved more in improving their own mental health
- More funding for intensive in-home therapy
- Support agencies for children of parents with mental illness. Workshops for families to understand issues of family members with illness
- We have the child-adolescent partial hospitalization program but then the children have no place to stay in the evenings. In order for children to remain in our community and even North Dakota, at this young age, we need more services. In foster care, when children are removed from the parental home, the parents lose Medicaid, which makes it difficult to access the services needed for reunification. Parents can make appointments at a HSC but there is a waiting list, so children drift in foster care until services can be accessed. The foster care placement ends up being longer and the children develop more issues which need more services – what a cycle! Never ending for many families. Resources are very limited in the foster care system.
- Make medications less burdensome on all not just the so-called low income/welfare people.
- More community awareness – sending information to agencies so they can share it with their clients
- Medicaid to develop rules and guidelines for: 1.) supervision of master’s level psychologist and clinical social workers to be supervised by doctoral level licensed psychologists 2.) Develop payment schedules appropriate for masters level professionals when they are supervised by a licensed psychologist
- More information and education in the schools and for the families on mental health needs

- Adequate and financially accessible day care and health care
- Increase funding for preventative services
- Open forums – flyers and increase in referrals from area physicians to services outside the medical field to help families receive respite services. Also grant money for special needs equipment not covered by insurance or medical assistance. Such as respite costs or bath equipment, home modifications or vehicle modifications.
- It would be great to have a stand alone pediatric care clinic to address these special needs.
- Pending the county I am working with, I feel that there needs to be consistent follow through of services provided for children once being discharged from a rehab center
- Children with autism often don't qualify for MI or DD services so have limited supports for families. Also, I work with a large number of children who do not qualify for ME or DD but would benefit from long term group care. There are also children who would benefit from a MI group home long term which are not available. We often struggle with utilization of DD group homes due to waiting lists and over a years waiting list these children often need these services before an opening occurs.
- Dickinson has excellent programs and services in place.
- There are lots of positive resources in our community. I believe that learning what there is and how to utilize them should be more coordinated and centralized. This would be helpful as sometimes one agency can cause barriers for being successful in accessing other services. Also, addressing several life domains of the family could be helpful.
- Better coordination of services – they are way too fragmented and parents are often poorly informed as to their right to access and what other service might assist them.
- I think you do a pretty good job overall.
- Need to educate people of service available. As a therapist even I don't know what's available to pass this info to families and I have live in this state for five years!
- Developmentally delayed children with behavioral issues need better accommodations in school and more community resources so they can stay at home. If we spent what we pay for hospitalization and group home care on the family these children could stay home.
- More community education regarding available services
- I think parents should be expected to be more involved with their children's appointments, recommendations made by the professionals, etc. If they persistently are not home at appointed times or don't do the homework, perhaps the courts need to become involved.
- Educate physicians and other health care providers about available services for such families so proper referrals can be made.